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Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, in accordance with Human Rights Council resolution 28.6.

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Report of the Independent Expert on the enjoyment of human rights by persons with albinism

Summary

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism looks at the international human rights standards pertaining to the human rights violations faced by persons with albinism and the correlating obligations for States. She discusses the implications for persons with albinism of the rights to equality and non-discrimination, life and freedom from torture and the importance of combating impunity, as well as efforts to combat harmful practices and trafficking in body parts. It also looks at specific aspects of the right to health, education, housing and work, which are particularly relevant to persons with albinism. Lastly, she considers how some aspects of international refugee law have been applied to persons with albinism.

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I. Introduction

1. In the vision of her mandate, the Independent Expert on the enjoyment of human rights by persons with albinism set several goals, including to "identify the applicable human rights legal framework and the key international human rights instruments that could both comprehensively and effectively address the human rights-related issues faced by persons with albinism in a sustainable way".[1] In the present report, she seeks to fulfil that objective.[2] In so doing, relevant international human rights treaties of general and specific application are identified. The interpretative aid of jurisprudence emerging from a variety of treaty bodies and other international human rights mechanisms, including those dealing specifically with persons with albinism, is also analysed. Lastly, the Independent Expert identifies key corresponding obligations of Member States for the full enjoyment of human rights by persons with albinism and makes practical recommendations in this regard.

II. Persons with albinism

2. People are affected by albinism throughout the world. However, the impact of the condition on human rights and its perception by others, including its effect on social inclusion, vary by region. The condition of albinism is non-contagious, genetically inherited and affects people regardless of race, ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in any or all of the skin, hair and eyes. Persons with albinism therefore often appear pale in comparison with members of their family and their communities. Today, it is estimated that in Europe and North America the frequency of albinism is 1 in 17,000 to 1 in 20,000 births. In sub-Saharan Africa, the reported frequency ranges from 1 in 5,000 to 1 in 15,000, with prevalence rates of 1 in 1,000 for selected populations. A higher frequency, 1 in 700, has been reported in certain parts of the Pacific and among some indigenous peoples in North and South America, 1 in 70 to 1 in 125.[3]

3. There are different types of albinism. The most well-known type is oculocutaneous albinism, which affects the skin, hair and eyes. Within this type are subtypes that may reflect varying degrees of melanin deficiency in an individual. Lack of melanin in the eyes results in high sensitivity to bright light and significant visual impairment, with the level of severity varying by person. This visual impairment often cannot be completely corrected. In addition, one of the most serious health implications of albinism is vulnerability to skin cancer, which remains a life-threatening condition for most persons with albinism in certain regions. All violations of civil and political rights relating to albinism reported to date have been linked to its oculocutaneous form, which is also the most visible type of albinism.

[1] See A/HRC/31/63, para. 47.

[2] See a complementary report by the International Bar Association with a thorough focus on sub-Saharan Africa and its regional human rights framework, available from **Error! Hyperlink reference not valid.**.

[3] The methodology of studies on the frequency of albinism is not homogenous and these numbers are to be understood as broad estimates.

III. International human rights standards of general and specific application and other sources of international law

4. In international human rights law, persons with albinism hold the same fundamental rights as any other individual or group. The Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights recognize human rights of general applicability to all people, including persons with albinism. These include the rights to life, physical integrity, liberty, security, equality and non-discrimination, the highest attainable standard of physical and mental health and an adequate standard of living.

5. International human rights law includes internationally recognized standards providing protection to specific groups through the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the International Convention on the Elimination of all Forms of Racial Discrimination and the Convention on the Rights of Persons with Disabilities. The last-mentioned instrument is of paramount significance for persons with albinism, in particular because of the duty set out therein to provide reasonable accommodation.

6. Other international human rights instruments, including in the area of international criminal law, in particular, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and the Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime, as well as international refugee law, may be invoked to ensure the full enjoyment of human rights by persons with albinism.

A. Equality, non-discrimination and intersectionality

7. Equality and non-discrimination are core principles of international human rights law, enforced on the basis of a non-exhaustive list of status or grounds set-out in every international and regional human rights instrument.

Intersectionality

8. Persons with albinism are a constituency of persons with disabilities and reports to the Independent Expert indicate that access to this protection framework is often granted to them on the basis of their visual impairment alone. Yet, studies indicate that persons with albinism also face discrimination stemming from their unusual appearance, in particular their colouring.[4] This suggests that persons with albinism encounter multiple and intersecting discrimination. Multiple discrimination is a situation where a person can experience discrimination on two or more grounds, in the sense that discrimination is compounded or aggravated.[5] Intersecting discrimination refers to a situation where several grounds for discrimination operate and interact with one another at the same time in such a way that they are inseparable.[6]

[4] Relebohile Phatoli, Nontembeko Bila and Eleanor Ross, "Being black in a white skin: beliefs and stereotypes around albinism at a South African University", in African Journal of Disability, vol. 4, No. 1, (2015).

[5] Committee on the Elimination of Discrimination against Women, general recommendation No. 25 (2004) on temporary special measures, para. 12.

[6] Committee on the Elimination of Discrimination against Women, general recommendation No. 28 (2010) on the core obligations of States parties under article 2 of the Convention, para. 18.

9. While the Convention on the Rights of Persons with Disabilities recognizes multiple and aggravated forms of discrimination, it does so substantively for women and children with disabilities.[7] There are no sections on racial issues except for a preambular reference to discrimination based on colour. Therefore, an approach based exclusively on the disability framework would fail to encompass the complexity of intersecting discrimination faced by persons with albinism based on colour. Thus, the combination of the Convention on the Rights of Persons with Disabilities and the International Convention on the Elimination of All Forms of Racial Discrimination provides more comprehensive protection and promotion of the human rights of persons with albinism.

10. Relying on various conventions to provide the most adequate protection is not new, it is the consequence of an increasing recognition of multiple and intersecting violations that may affect a person or group.[8] These approaches have been used in human rights law to better map out violations faced, to grasp the depth of the consequences and to design practical and useful interventions. The last-mentioned goal is particularly useful for an emerging group, such as persons with albinism, who in several countries had little or no practical protection until the past decade.

11. Furthermore, the notion of multiple and intersecting discrimination affecting persons with albinism is firmly rooted in international human rights jurisprudence. In that respect, treaty bodies have applied non-discrimination provisions of human rights treaties to the situation of persons with albinism.

12. For example, the Committee on Economic, Social and Cultural Rights has recognized persons with albinism as a specific group facing discrimination.[9] The Committee on the Rights of the Child has also condemned persistent discrimination against children with albinism.[10]

13. In addition, the Human Rights Committee has addressed discrimination against persons with albinism under the heading "non-discrimination against vulnerable groups". The Committee has highlighted its concern at the stigmatization of and discrimination against persons with albinism.[11] Furthermore, the Committee on the Elimination of Discrimination against Women has expressed deep concern regarding the discrimination, stigmatization and social exclusion faced by persons with albinism. The Committee on the Elimination of Discrimination against Women has also addressed the situation of women with albinism under the concept of disadvantaged groups of women, noting the multiple forms of discrimination that they face.[12] Lastly, in recognition of the aggravated forms of discrimination faced by persons with albinism, the Committee on the Rights of Persons with Disabilities stated that persons with albinism were some of the most stigmatized and that legal protection against disability-based discrimination should be combined with protective

[7] Convention on the Rights of People with Disabilities, arts. 6-7.

[8] This was stressed by the Committee on the Rights of Persons with Disabilities in the context of persons with albinism (See CRPD/C/UGA/CO/1).

[9] International Covenant on Economic, Social and Cultural Rights, art. 2.2. The Committee on Economic, Social and Cultural Rights, general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, states: "Some individuals or groups of individuals face discrimination on more than one of the prohibited grounds, for example women belonging to an ethnic or religious minority. Such cumulative discrimination has a unique and specific impact on individuals and merits particular consideration and remedying". See also E/C.12/BFA/CO/1, E/C.12/BDI/CO/1, E/C.12/UGA/CO/1, E/C.12/COD/CO/4 and E/C.12/TZA/CO/1-3.

[10] See, for example, CRC/C/CAF/CO/2, CRC/C/COD/CO/3-5, CRC/C/MWI/CO/3-5, CRC/C/ZAF/CO/4-8, CRC/C/TZA/CO/3-5, CRC/C/COG/CO/2-4 and CRC/C/KEN/CO/3-5.

[11] See CCPR/C/GHA/CO/1, CCPR/C/MWI/CO/1/Add.1, CCPR/C/BDI/CO/2, CCPR/C/TZA/CO/4, CCPR/C/KEN/CO/3 and CCPR/C/CIV/CO/1.

[12] See CEDAW/C/BDI/CO/5-6, CEDAW/C/TZA/CO/7-8, CEDAW/C/SWZ/CO/1-2 and CEDAW/C/MWI/CO/7.

measures against multiple and intersecting forms of discrimination faced by persons with disabilities, including persons with albinism.

Prohibition of discrimination based on disability

14. Persons with disabilities include those with long-term impairments, whether physical, mental, intellectual or sensory, which in interaction with various barriers may hinder full and effective participation in society, including the enjoyment of rights, on an equal basis with others. This approach to disability moves away from the charitable and medical models, which did not focus on the human rights and corresponding duties of the State vis-à-vis their citizens with disabilities. These older approaches also tended to exclude persons with albinism, as they were often seen as either not having physical disabilities or were categorized as "blind". While the human rights approach has taken hold normatively, as represented by the Convention on the Rights of Persons with Disabilities, the older approaches still persist and tend to hinder the enjoyment of human rights by persons with albinism. Nonetheless, the Convention offers a firm foundation for standards to which States parties can be held in their attempts to promote and protect the rights of persons with disabilities, including persons with albinism.

15. Equality and non-discrimination are enshrined in article 5 of the Convention on the Rights of Persons with Disabilities. Article 2 defines discrimination on the basis of disability and stresses that "it includes all forms of discrimination, including denial of reasonable accommodation", a substantive concept necessary to enable the exercise of rights on an equal basis with others.[13] The prohibition of discrimination on the basis of disability includes discrimination by association with a person with a disability, where a person without a disability is discriminated against based on any broad range of connections to a person with a disability. Mothers of children with albinism, for example, often face strong social stigma, discrimination and exclusion and would therefore fall under the normative protection of this clause.

16. In addition to article 5 of the Convention on the Rights of Persons with Disabilities, many provisions have been applied specifically to persons with albinism by the Committee on the Rights of Persons with Disabilities, including in its concluding observations on Kenya, Ethiopia and Uganda, in which specific references were also made to the relevance of article 8, on awareness-raising, article 10, on the right to life, article 19, on living independently and being included in the community, and article 25, on health.[14] The Committee has also stressed the importance of the involvement of representative organizations of persons with albinism in the framework of the implementation of recommended measures.[15]

Prohibition of racial discrimination on the ground of colour

17. An underlying factor at the heart of discrimination against persons with albinism is their visibility, owing to the pale or light colouring of any or all of the skin, hair and eyes. The appearance of persons with albinism makes them hypervisible, in particular in environments where the majority of the population have darker pigmentation, resulting in a stark contrast between the two groups, as is the case in sub-Saharan countries where attacks are reported.

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[13] Defined in article 2 of the Convention on the Rights of Persons with Disabilities as the "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".

[14] See CRPD/C/ETH/CO/1, CRPD/C/UGA/CO/1 and CRPD/C/KEN/CO/1.

[15] See CRPD/C/UGA/CO/1.

18. Under article 1 of the International Convention on the Elimination of All Forms of Racial Discrimination, racial discrimination is a distinction and an exclusion, restriction or preference based on, inter alia, colour which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise of human rights and fundamental freedoms in the political, economic, social, cultural fields or any other field of public life on an equal footing with others. The grounds for discrimination listed in article 1 do not need to be combined, and discrimination based on any one of these triggers not only the applicability of the Convention, but also all the instruments applicable in the efforts to combat racial discrimination.[16]

19. Accordingly, the International Convention on the Elimination of all Forms of Racial Discrimination has recognized that persons with albinism, who are discriminated against on the basis of their colour, albeit often being of the same race, descent, national and ethnic origin as those who persecute them, face a manifestation of racial discrimination.[17]

20. The manifestations of discrimination against people with albinism on the basis of colour include harmful practices and violence, consisting of, but not limited to, physical attacks, mutilation and trafficking in body parts — all motivated in part by witchcraft beliefs and practices as reported in 27 countries in sub-Saharan Africa.

21. The Committee has expressed concern at the "discrimination and stigmatization faced by persons with albinism, on the basis of their colour"[18] and has subsequently recommended the implementation of effective measures to protect persons with albinism in action plans and other measures taken to implement the Durban Declaration and Programme of Action.

Prohibition of gender-based discrimination

22. Women and girls with albinism are victims of multiple discrimination including physical attacks, mutilation, rape, forced expulsion, domestic violence, abandonment and trafficking of body parts. Women who have a child with albinism are also the subject of multiple discrimination.

23. Mothers of children with albinism, including those who do not have albinism, are frequently blamed for "causing" the albinism of their children, accused of infidelity or having contracted a curse. Such social pressure and blame, which often comes from their spouses or partners, extended family members and society, puts women in a situation where they have to choose between abandoning their child or face abandonment by their husbands. It may also means expulsion from the community, social isolation (both self and community inflicted) to escape abuse and quarantine the perceived "curse".

24. As a result of abandonment, mothers of children with albinism often face poverty upon having the child with albinism. This exposes their child with albinism to further poverty confinement as it negatively affects the child's access to education and often pushes the child into child labour.

25. Women whose spouses were involved in attacks against their child with albinism often face threats of reprisal from their extended family and the community at large after testifying against their husbands in the investigation and prosecution of attacks.

[16] See CRC/C/ZAF/CO/2.
[17] Ibid.
[18] See CERD/C/ZAF/CO/4-8, para. 20.

26. The Committee on the Elimination of Discrimination against Women recognizes the intersecting forms of discrimination that affect women with albinism. The Committee has also addressed harmful practices specifically affecting women with albinism, including the practice of prescribing sex with girls or women with albinism as a cure for HIV/AIDS and the stigma and social exclusion suffered by mothers of children with albinism.[19] The Committee has also expressed its concern at the low number of prosecutions and convictions of cases of attacks against persons with albinism.[20] The combined effect of gender-based discrimination and discrimination against persons with albinism multiplies the barriers for women with albinism or mothers of children with albinism in gaining access to justice.

Prohibition of discrimination against children

27. Children with albinism face a very high risk of infanticide and, together with their mothers or on their own, abandonment.[21] In the absence of adequate birth and death registration systems and detailed census records targeting persons with albinism, there are no reliable statistics on these crimes and, therefore, cases are likely to go unreported and uninvestigated. It also means that early intervention in the areas of health, in particular skin cancer prevention and reasonable accommodation relating to visual impairment, is difficult to plan for as there are no data to guide the planning and policy making processes.

28. In addition, myths linked to the innocence of children and the alleged superpower of the body parts of children with albinism makes then a preferred target of attacks. The involvement of family members in a large number of reported attacks and the vulnerability of children who are easy to capture because they lack the physical strength necessary to defend themselves further increase this risk.

29. The Committee on the Rights of the Child has expressed concern at the violence perpetrated against children with albinism, who are subjected to rituals amounting to torture, cruel, inhuman or degrading treatment, kidnapping and death and stressed the high risk of expulsion of children with albinism from their families and a correlating vulnerability to trafficking.[22] The Committee has also expressed concern at other effects of discrimination against children with albinism leading to school dropout.[23] The particular vulnerability of children with albinism in cases of abandonment or where a family member is involved in an attack against them is especially concerning and has a strong impact on their access to remedies and protection.

B. Civil and political rights

Right to life

30. The right to life and physical integrity of persons with albinism is systematically violated in the context of attacks, killings, mutilations and abandonment. The right to life is recognized in several human rights instruments, in particular in the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights. Not only is the right to life non-derogable, it is also essential for the enjoyment of all human rights. Therefore, the protection of the right to life of persons with albinism living in countries where attacks and killings are taking place represents a priority issue to be addressed by the States concerned.

[19] See CEDAW/C/TZA/CO/7-8.
[20] See CEDAW/C/BDI/CO/5-6, CEDAW/C/TZA/CO/7-8 and CEDAW/C/SWZ/CO/1-2.
[21] See A/HRC/24/57.
[22] See CRC/C/CAF/CO/2.
[23] See CRC/C/MWI/CO/3-5.

31. Furthermore, in all regions, the right to life of persons with albinism is also threatened by the lack of awareness and adequate measures regarding their vulnerability to skin cancer, resulting in a shortened life expectancy. Reduced life expectancy may also be due to other factors such as the lack of reasonable accommodation regarding visual impairment, which limits employability and forces outdoor work that, in turn, catalyses skin cancer and early death. Other factors leading to reduced life-expectancy include induced isolation owing to stigmatization and discrimination and the related vulnerability to attack, barriers in access to health services and reduced opportunities for adequate living conditions.

32. In addition, a range of human rights are protected under the norms of and jurisprudence relating to International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child, including the rights to equality and non-discrimination, the highest attainable standard of mental and physical health, education, work and reasonable accommodation. All must be upheld in order to address and mitigate the factors contributing to shortened life expectancy for persons with albinism.

Prohibition of torture and inhuman and degrading treatment

33. The intensity of the attacks against persons with albinism undeniably causes severe pain and suffering to victims, considering that, in many cases, limbs are severed while the victim is still alive in order to increase the wrongly attributed potency of the body parts in witchcraft practices such as muti or juju.[24] Furthermore, this pain is intentionally inflicted on persons with albinism on the basis of erroneous myths and discrimination surrounding their condition.

34. To amount to torture, however, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment requires, in article 1, that, in addition to intensity of pain and intention, the act of torture should be committed "at the instigation, or with the consent or acquiescence, of a public official or other person acting in an official capacity".

35. When an official is involved at any stage, including as an end user of the body parts, or when, and this is the most common situation in attacks against persons with albinism, the act is tolerated by the Government, this criterion of the definition of torture is met. This acquiescence can take the form of an omission to act or take adequate steps in response to such acts, including the lack of investigation, even when no complaints have been filed by the family of the victim. In the same vein, official acquiescence also extends to the failure to prosecute, or the pronouncing of a sentence that is clearly not commensurate with the gravity of the crime. State responsibility also arises where national authorities are "unable or unwilling" to provide effective protection from ill-treatment. In other words, they fail to prevent or remedy such acts of torture and ill-treatment, including those perpetrated by non-State actors.[25]

36. The Committee against Torture has examined the particular situation of persons with albinism and emphasized that persecution and physical assaults leading to the death and mutilation of persons with albinism would fall under the

[24] See A/HRC/24/57 and A/HRC/34/59.

[25] See quote of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment, in Office of the United Nations High Commissioner for Human Rights, *Combating Torture: Human Rights Fact Sheet*, No. 4/Rev.1 (Geneva, 2002), p. 34.

scope of the Convention.[26] Among the elements considered by the Committee is the impunity of perpetrators of such crimes. The Committee on the Rights of the Child has also stressed that "violence perpetrated against children with albinism ... amount[s] to torture, cruel, inhuman or degrading treatment, kidnapping and even death".[27]

Combating impunity

37. Failure to combat the impunity of perpetrators of attacks against persons with albinism is a major issue that has been raised by various committees.[28] They have all pointed to the obligation of States to investigate and prosecute all cases of attacks and to ensure the adequacy of the national legislative framework and criminal sanctions. The Independent Expert has also stressed this issue, and explained that particular vigilance by the State is necessary in these cases, as a result of unique factors surrounding violence faced by persons with albinism, including the participation of family members, and the correlating issue of underreporting of cases.[29] As stated by the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, combating impunity has different implications for a State, including carrying out an investigation even in the absence of formal complaints and the obligation to hold perpetrators accountable.[30]

38. The Independent Expert noted during her mission to Malawi[31] that one of the main manifestations of impunity in the context of attacks resided in the early return of suspects to their communities, whether as a result of raising bail, paying fines, light sentences or other measures facilitating early release. Perceived impunity for crimes against persons with albinism not only significantly reduces the deterrent effect of the law, but also can, in certain cases, contribute indirectly to lynching and "mob justice".

39. To combat impunity, States have an obligation to ensure that all acts of torture are offences under its criminal law and that those offences are punishable by appropriate penalties. In this regard, national criminal frameworks very often do not contemplate the forms of attack against persons with albinism. This can lead to legal gaps, or to the use of inadequate legal provisions, such as those for dealing with trafficking in body parts that are not organs.

Prohibition of harmful practices

40. Harmful practices are defined in joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices as "persistent practices and forms of behaviour that are grounded in discrimination on the basis of, among other things, sex, gender and age, in addition to multiple and/or intersecting forms of discrimination that often involve violence and cause physical and/or psychological harm or suffering".

41. According to the Committee on the Elimination of Discrimination against Women, "the practice of prescribing sex with girls or women with albinism as a cure for HIV, ritual killings and attacks on persons with albinism, including women and girls, the use of their body parts for purposes of witchcraft, and the stigma and

[26] See CAT/C/BDI/CO/2.
[27] See CRC/C/CAF/CO/2.
[28] See, for example, CRC/C/COD/CO/3-5, CRC/C/MWI/CO/3-5, CRPD/C/ETH/CO/1 and CEDAW/C/TZA/CO/7-8.
[29] See A/HRC/34/59.
[30] See A/54/426.
[31] See A/HRC/34/59/Add.1.

social exclusion suffered by mothers of children with albinism"[32] constitute harmful practices.

42. Such practices indeed fall under the non-cumulative criteria established by both committees in their joint general recommendation/general comment and "constitute a denial of the dignity and/or integrity of the individual and a violation of ... human rights".[33] Furthermore, given the myths that tend to dehumanize and facilitate attacks against persons with albinism;[34] these practices also "result in ... physical [and] psychological, ... harm and/or violence".[35]

43. These attacks are "traditional, re-emerging or emerging practices that are prescribed and/or kept in place by social norms".[36] While the origin in time of such attacks is unclear, the presence of age-old myths suggesting systemic "disappearances" of persons with albinism and more recent waves of attacks reported in various countries, both by civil society and Governments, suggest emerging, or possibly, re-emerging practices. Lastly, such practices are "imposed ...) by family members, community members or society at large".[37]

Prohibition of trafficking in persons and trafficking in body parts

44. The existence of a black market for body parts for the purpose of muti or juju at the national, regional and international levels has often been alluded to by civil society and Governments of affected countries and illustrated by elements such as the detention of people in possession of body parts of persons with albinism.

45. In their concluding observations, both the Human Rights Committee and the Committee on the Rights of the Child addressed trafficking in body parts.[38]

46. Although further investigative studies and research are needed to map patterns of trafficking in body parts, including on the alleged markets or points of sale and the international networks that may be involved, available information has been sufficient to reveal that a gap exists in the existing legal framework on the issue.

47. The main international instrument regarding trafficking in persons is the Protocol to Prevent, Suppress and Punish Trafficking in Persons. It requires three elements for an act to constitute trafficking: (a) an act — the recruitment, transportation, transfer, harbouring or receipt of persons; (b) a means — the use of force, coercion, abduction, fraud, deception, abuse of power or vulnerability, or giving payments or benefits to a person in control of the victim; and (c) a purpose — including exploiting the prostitution of others, sexual exploitation, forced labour, slavery or similar practices and the removal of organs. No cross-border element is required.

48. Yet, the Protocol addresses trafficking in persons as such and not trafficking in body parts, even if one of the purposes of trafficking in persons could be, at a later stage, the removal of organs. Therefore, kidnapping for the purpose of removing body parts could be considered to fall within the definition of trafficking in persons, but being in possession of body parts would not.[39]

[32] See CEDAW/C/TZA/CO/7-8, para. 18; CEDAW/C/MWI/CO/7, para. 20.
[33] Joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18.
[34] See A/71/255, para. 13.
[35] Joint general recommendation No. 31/general comment No. 18 (2014), para. 16 (b).
[36] Ibid., para. 16 (c).
[37] Ibid., para. 16 (d).
[38] See CCPR/C/MOZ/CO/1 and CRC/C/TZA/CO/3-5, respectively.
[39] See A/68/256.

49. The Council of Europe Convention against Trafficking in Human Organs may also fall short. In article 2, a human organ is defined as "a differentiated part of the human body, formed by different tissues, that maintains its structure, vascularisation and capacity to develop physiological functions with a significant level of autonomy". Both the scope and the definition of a human organ are very precise and have not been drafted as open-ended lists. Accordingly, body parts such as limbs, arms and legs, ears, fingers, hair and bones, often stolen in the context of attacks against persons with albinism, do not fall under this definition.

50. Other instruments do not directly exclude body parts, but are yet to be interpreted to include body parts that are not organs. For example, the Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography states that the "transfer of organs of the child for profit" should be a criminal offence. "Organ" is not defined in the Protocol nor in the reporting guidelines of the Committee.

C. Economic, social and cultural rights

Right to health

51. The right of persons with albinism to the highest standard of physical and mental health is firmly recognized in international human rights law. The International Covenant on Economic, Social and Cultural Rights provides the most comprehensive normative framework on this right in article 12. It includes an adequate system of health protection, the right to prevention and treatment of illnesses, the right of access to essential medicines and the provision of health-related education and information, as well as participation of those concerned in health-related decisions.[40]

52. Accordingly, all States Parties to the Covenant are to take all appropriate measures to ensure access for persons with albinism to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties are to provide health care equal to that provided to other persons, tailored health services for the condition of albinism and health services as close as possible to people's own communities. They are to require health professionals to provide care of the same quality to persons with albinism as to others, prohibit discrimination against persons with albinism in the provision of health insurance and prevent discriminatory denial of health care based on disability or colour. In this regard, the Convention on the Rights of Persons with Disabilities in article 25 echoes and recognizes the right to the enjoyment of the highest attainable standard of health without discrimination on the ground of disability. Article 1 of the International Convention on the Elimination of All Forms of Racial Discrimination would also apply.

53. States have a duty to provide reasonable accommodation for the visual impairment of persons with albinism in order to ensure de facto equality with others in society. States, in particular their health sector, also have a duty to ensure that health-care information and specific prevention and curative measures against skin cancer such as sunscreen and sun protective clothing are affordable, accessible and available, even in rural areas, from birth and throughout life. Specialized information on specific care to prevent skin cancer and on usage of sunscreen should also be widely disseminated.

[40] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) on the right to the highest attainable standard of health.

54. The treatment, both preventive and curative, of skin cancer is a matter of life and death for persons with albinism. This risk is linked not only to the fatal issue of cancer, but also to the fact that pre-cancerous and cancerous lesions are often so disfiguring that they contribute to dehumanizing myths, which in turn facilitate and justify attacks.

55. Persons with albinism are sometimes turned away by health professionals who fear contagion or bad luck or simply find them visibly repugnant or undeserving of treatment. It is highly important to address discrimination against persons with albinism in access to health. Interventions in this regard should also take into account the reality of persons with albinism living with HIV/AIDS, — a relatively high number in some countries, worsened by myths that albinism can cure the condition — who are unable or unwilling to gain access to the necessary treatment owing to the minimal confidentiality resulting from their hypervisibility and the consequent fear of further stigma, because of the discrimination still commonly associated with HIV/AIDS.

Right to education

56. The right to education is a fundamental human right and has a solid basis in international human rights law. It is an "empowerment right" and an indispensable means of realizing other rights.

57. Multiple and intersecting forms of discrimination against persons with albinism have an impact on the realization of their right to education. Discrimination, social stigma, superstitions and myths surrounding their physical condition, coming from both staff and students alike, violence, poverty, the absence of appropriate infrastructure, a lack of security in the wake of attacks and the absence of reasonable accommodation, learning material and methods, as well as a lack of sufficiently trained personnel, all constitute key factors explaining the low school attendance, and high dropout rates of persons with albinism. A lack of education or substandard education is a matter of life and death for persons with albinism, as it confines them to poverty and outdoor jobs that in turn expose them to skin cancer and poverty, both of which lead to early death and vulnerability to attack.

58. Persons with albinism worldwide are highly vulnerable to school-related violence (bullying) and physical and verbal abuse[41] owing to their distinctive colouring and appearance. This violence and abuse are often closely linked to the predominance of misconceptions, prejudices and superstitions about albinism, even in countries where witchcraft practices, such as muti or juju, are virtually non-existent.

Right to adequate housing

59. The right to housing is firmly anchored in international human rights law,[42] which recognizes "the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the

[41] In 2014, the organization Under the Same Sun gathered 182 different insulting names for a person with albinism, from dozens of languages. See http://www.underthesamesun.com/sites/default/files/Names%20used%20for%20PWA.pdf.

[42] The right to adequate housing is notably recognized by the International Covenant on Economic, Social and Cultural Rights (art. 11), the Convention on the Rights of Persons with Disabilities (art. 28), and the International Convention on the Elimination of All Forms of Racial Discrimination (art. 5 (e) (iii)), the Convention on the Rights of the Child (arts. 16 (1) and 27 (3)) and the Convention on the Elimination of All Forms of Discrimination against Women (arts. 14 (2) and 15 (2)).

continuous improvement of living conditions".[43] Furthermore, it entails freedoms, such as protection against forced eviction, freedom from arbitrary interference with one's home, privacy and family, freedom of movement and entitlements, including security of tenure, land and property restitution, equal and non-discriminatory access to adequate housing and participation in housing-related decision-making at the national and community levels.

60. Regarding access to housing, the Special Rapporteur on the rights of persons with disabilities reported, after her country visit to Zambia, that stigma and discrimination also had a negative impact on the right to adequate housing of persons with albinism, as landlords often feared renting their accommodation to persons with albinism on the basis that "they would run away overnight to escape attack, leaving their bills unpaid".[44] Similar reports have also since reached the Independent Expert, whereby tenancy to persons with albinism was denied by landlords who feared being implicated in attacks, while other landlords feared bad luck striking their enterprise by having persons with albinism as tenants.

Right to work

61. The right to work is firmly recognized in international human rights law in several human rights treaties, in particular in articles 6 and 7 of the International Covenant on Economic, Social and Cultural Rights. The right to work requires decent work, namely:

> "Work that respects the fundamental rights of the human person as well as the rights of workers in terms of conditions of work safety and remuneration. It also provides an income allowing workers to support themselves and their families as highlighted in article 7 of the Covenant. These fundamental rights also include respect for the physical and mental integrity of the worker in the exercise of his/her employment."[45]

62. Just as other persons with disabilities, and persons discriminated against on the basis of their colour, persons with albinism face a significant challenge securing high-quality employment. The colouring of persons with albinism in particular is used as basis to deny employment on the ground that it would drive clients away or create a perception of contagion, in particular in the food or hospitality industry.

63. Furthermore, securing indoor employment remains a major challenge for a significant number of persons with albinism. Resorting to agriculture and peddling, while often viable forms of self-employment, puts persons with albinism at risk of skin cancer. In countries with records of attacks against persons with albinism, the absence of work in a secure environment produces endemic fear and has an impact on their livelihood, given that insecurity often shortens the number of work hours that they are able or willing to risk carrying out away from home. A similar impact on the right to work of family members and carers of persons with albinism has also been reported to the Independent Expert.

[43] International Covenant on Economic, Social and Cultural Rights, art. 11.

[44] See A/HRC/34/58/Add.2, para. 28.

[45] Committee on Economic, Social and Cultural Rights, general comment No. 18 (2005) on the right to work, para. 7.

D. International refugee law

Right to asylum

64. As a consequence of a high level of stigmatization and discrimination, persons with albinism have fled their countries and requested asylum in countries thought to be safer. In this regard, one of the most complex elements to establish in order to be granted refugee status is the need to link a well-founded fear of being persecuted to an enumerated ground for such status, namely, race, religion, nationality, political opinion or membership of a particular social group.[46]

65. The Office of the United Nations High Commissioner for Refugees (UNHCR), in a study[47] seeking to clarify the meaning of "particular social group", has examined jurisprudence from around the world and noted that various jurisdictions have addressed the question of whether albinism could fall under this category. This is the case for the Immigration and Protection Tribunal of New Zealand, which held that "albinism is an immutable characteristic which is beyond the power of the appellant to change, and is an internal defining characteristic which serves to define the group independently of the persecution".[48] The same decision also stressed that "albinos are properly considered a particular social group in Egypt".[49] A French jurisdiction also considered that persons with albinism were part of a specific social group, but this time on the basis of how they were perceived, the myths and stigma and the ostracism that they faced.[50] However, the study concluded that the criteria of membership of a particular group still lacked clarity.

66. Despite this debate, asylum has been granted to persons with albinism. France,[51] for example, has granted asylum to a woman from Nigeria with albinism who had been blamed, because of her albinism, for the death of men in her clan and fled to France. The reasoning behind the decision stressed that traditions and customs relating to albinism, particularly vivid in that country, combined with the lack of protective measures for that high-risk group, created a real risk of persecution if she were to return to Nigeria. Civil society organizations also reported that various countries had been granting asylum to persons with albinism based on the persecution that they face.[52]

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[46] Convention relating to the Status of Refugees, art. 1.

[47] Michelle Foster, "The 'ground with the least clarity': a comparative study of jurisprudential developments relating to 'membership of a particular social group'", Legal and Protection Policy Research Series (Geneva, Office of the United Nations High Commissioner for Refugees (UNHCR), 2012).

[48] *AC (Egypt)*, [2011] NZIPT 800015, New Zealand: Immigration and Protection Tribunal, decision of 25 November 2011.

[49] Ibid.

[50] Commission des recours des réfugiés (French Refugees Appeal Board), decision of 10 June 2005, M.T. n° 04041269/514926 R; Cour nationale du droit d'asile (French National Court of Asylum), n°629447, 28 April 2009.

[51] Commission des Recours des Réfugiés (French Refugees Appeal Board), decision of 29 August 2006, Melle. AO, n°545655.

[52] This was the case in the United Kingdom of Great Britain and Northern Ireland for a man with albinism from Cameroon in 2015, in Ireland for a man with albinism from the Democratic Republic of the Congo in 2015, in Canada for a man with albinism from Guinea in 2013, in Belgium for a woman and her son with albinism from Guinea in 2015, in Tunisia for a woman with albinism and her two children from Côte d'Ivoire, in France for a lady from Mali in 2011, in the United States of America for a man with albinism from Nigeria, a man with albinism from Senegal, and a woman with albinism from Zimbabwe. See www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf.

Rights of internally displaced persons

67. The displacement of a significant number of persons with albinism has been reported, for example, in Burundi and the United Republic of Tanzania,[53] as a result of generalized violence or specific persecution based on albinism. In situations of forced displacement, persons with albinism face particular protection risks, not due only to their visual impairment and specific health risks, but also to myths and beliefs linked to albinism, which may be alive in camps for internally displaced persons or refugees owing to pre-existing perceptions of the condition or brought by other refugees and displaced persons. The situation of distress of people displaced and the destruction of trusted social networks of persons with albinism are among the many factors that can further aggravate the insecurity of internally displaced persons with albinism.

68. In response, and in addition to the implementation of the existing framework, including the Guiding Principles on Internal Displacement, UNHCR has adopted specific protection measures for persons with albinism. An example of the UNHCR practice is the transfer of a girl and her mother from a refugee camp in the United Republic of Tanzania following two kidnapping attempts on the girl.[54] Another example is a partnership between UNHCR and the non-governmental organization Albinos sans frontières which provides support to persons with albinism fleeing persecution in the Democratic Republic of the Congo.[55]

69. Displacement as a specific protection measure for persons with albinism has also been considered. In response to the significant number of attacks in regions of the United Republic of Tanzania, the Government has established temporary holding centres as "safe houses" for children with albinism. This temporary solution has become a long-term situation, however, and the African Committee of Experts on the Rights and Welfare of the Child noted in its investigative report on the situation of children with albinism that the temporary shelter visited in the country "resembles more of a preventative detention facility than a safe house".

IV. International human rights obligations

A. Core obligations

70. Under international human rights law, every person is entitled to freedom from fear and freedom from want and to equality and non-discrimination, a core principle. The right to life and to be protected from torture may not be derogated from under any circumstance.[56]

71. Considering the principle of the interdependence and indivisibility of human rights, the right to life serves as an enabling and protection right necessary for the enjoyment of all other human rights. Conversely, the right to life also depends on the enjoyment of other human rights. In this regard, States have a core obligation to

[53] International Federation of Red Cross and Red Crescent Societies, "Through the albino eyes: the plight of albino people in Africa's Great Lakes region and a Red Cross response" (Geneva, 2009). Available from www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf.

[54] Nathalie Bussien and others, *Breaking the Spell: Responding to Witchcraft Accusations against Children*, New Issues in Refugee Research, Research Paper No. 197 (Geneva, UNHCR, 2011).

[55] Bertrand Ntwari, "UNHCR helps young Congolese albino on the run from witchcraft", Leo R. Dobbs, ed., 14 October 2013. Available from www.unhcr.org/news/stories/2013/10/525be9c89/unhcr-helps-young-congolese-albino-run-witchcraft.html.

[56] International Covenant on Civil and Political Rights, art. 4 (3).

ensure the satisfaction of, at the very least, minimum essential levels of economic and social rights.[57]

72. States parties to international human rights treaties are legally bound to international obligations to respect, protect and fulfil all human rights, to which they must give effect in good faith. All branches of the State, including local authorities, must comply with these obligations. This is particularly important regarding the situation of persons with albinism often living in remote areas.

73. States also have to seek better understanding of the root causes of attacks and the specificities of such attacks, including trafficking in body parts, as these would facilitate the work of law enforcement agencies in protecting life and in preventing torture. In the same vein, the State also has a duty to take positive measures to prevent reoccurrences of violations of these rights.

74. The duty of the State to protect the right to life and prevent torture also requires the systematic recording of attacks. Furthermore, States are to disseminate information widely to promote awareness within the law enforcement community and to ensure that adequate measures are developed where necessary. Moreover, States are to undertake and support research, systematic collection of data, and thorough analysis of risk factors. Preventing crimes relating to attacks against persons with albinism encompasses the adoption of strategies and measures.

75. States also have to ensure the minimum essential levels of economic and social rights for persons with albinism. They must guarantee the right to equality and non-discrimination, including reasonable accommodation, to persons with albinism as a core obligation considering its centrality in international human rights law.

B. Obligations to ensure equality and non-discrimination

76. International human rights law recognizes the obligation to adopt specific measures necessary to accelerate or achieve de facto equality, including affirmative action measures.[58] These measures are aimed at securing the advancement of certain groups or individuals requiring specific protection for the full enjoyment of human rights. Essentially, the measures are to attenuate or suppress conditions that perpetuate discrimination. While such measures are often considered to be limited in time until substantive equality is achieved, it is also recognized that there are exceptions. For example, the Committee on Economic, Social and Cultural Rights states that "such positive measures may exceptionally, however, need to be of a permanent nature, such as interpretation services for linguistic minorities and reasonable accommodation of persons with sensory impairments in accessing health-care facilities".[59]

77. Therefore, the framework of international human rights obligations that applies to persons with albinism includes the obligation to adopt special measures aimed at redressing and accelerating de facto equality and the adoption of permanent special measures, such as reasonable accommodation for visual impairment and vulnerability to skin cancer. According to article 5 (3) of the Convention on the Rights of Persons with Disabilities, States parties must take all appropriate steps to

[57] Committee on Economic, Social and Cultural Rights, general comment No. 3 (1990) on the nature of States parties' obligations.

[58] Convention on the Elimination of All Forms of Discrimination against Women, art. 4 and International Convention on the Elimination of All Forms of Racial Discrimination, arts. 1 (4) and 2 (2), Convention on the Rights of Persons with Disabilities, art. 5 (4).

[59] Committee on Economic, Social and Cultural Rights, general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, para. 9.

ensure that reasonable accommodation is provided. Furthermore, the Convention places an obligation on the State to ensure that discriminatory barriers are removed, by both eliminating and preventing discriminatory action.

78. States also have the obligation to promote a positive perception, including by combating stereotyping, stigmatization and discrimination. Albinism is indeed profoundly misunderstood and long-term ignorance about the condition has given birth to myths, which are often extremely concerning. A number of such myths have the effect of stripping persons with albinism of their humanity, paving the way for exclusion and attacks. The misunderstanding of the condition has also led to name-calling, verbal abuse and discrimination, as well as constant social discrimination for school-aged children with albinism throughout the world.

C. Progressive realization and immediate obligations

79. The obligation to progressively achieve the full realization of economic, social and cultural rights is closely related to the obligation of States to take appropriate measures towards their full realization, taking into account the maximum of their available resources. This recognizes the cost of fully implementing these measures and an implicit consequence that they might be achieved only over a period of time.

80. There is an immediate obligation to take appropriate steps for the realization of those rights. A lack of resources cannot justify inaction, but should be taken into account when evaluating the efforts carried out by a State to implement these rights. Furthermore, certain economic, social and cultural rights are not subject to progressive realization, based on their nature, such as the right to participate in cultural life or to form trade unions, while others have strict time-bound limits, such as the obligation to develop a plan of action to ensure the provision of free and compulsory primary education for all within two years. There are similar obligations to meet the minimum essential levels for each right. States are also not allowed to reduce the standards of implementation of rights already reached unless doing so can be adequately justified.

81. The obligation not to discriminate while undertaking to guarantee a right, which is fundamental to prevent the human rights violations faced by persons with albinism, is an immediate obligation. Similarly, the obligation to provide reasonable accommodation applies immediately to all rights.

D. Obligations to respect, protect and fulfil all human rights

82. The obligation to respect requires States to refrain from taking any discriminatory action or any measure infringing the exercise of human rights. This includes measures that limit or deny access to goods and services, including reasonable accommodation, for persons with albinism, and ultimately limit the enjoyment of economic and social rights, such the right to food, housing or health.

83. The obligation to protect is of utmost importance in the case of attacks. Here, States tend to fail to protect persons with albinism against acts committed by private persons or entities. States must also protect persons with albinism from discrimination by private entities or persons. In this context, the duty of due diligence must be reaffirmed, requiring States to take the appropriate measures to prevent, punish, investigate or redress the harm caused by such acts by private

persons or entities.[60] Considering its potential effect of deterrence, due diligence is thus a measure of protection.

84. In the context of rising cases of attacks, States have the obligation to provide effective remedy. Given the persistent impunity on the matter, States must adopt "provisional or interim measures to avoid continuing violations and to endeavour to repair at the earliest possible opportunity, any harm that may have been caused by such violations".[61]

85. The obligation to fulfil human rights requires States to take all the steps necessary to create a necessary and conducive environment for the enjoyment of human rights. In the case of civil and political rights, States should take the steps necessary to ensure the legal framework, functioning institutions and adequate resources for their enjoyment. With regard to economic, social and cultural rights, States must fulfil these rights in a situation where a person or a group is unable, for reasons beyond their control, to enjoy these rights.

86. In the context of economic, social and cultural rights, States have the core obligation to ensure access to the right to health, education, housing and employment on a non-discriminatory basis, especially for vulnerable or marginalized groups such as persons with albinism.[62] In the case of the right to health, States are to refrain from prohibiting or impeding traditional preventive care, healing practices and medicines (obligation to respect), while ensuring that harmful practices do not interfere with the right to life and physical integrity and health (obligation to protect). Equally important, States have the obligation to disseminate appropriate information relating to, inter alia, albinism and harmful practices, and ensure that sun protection creams and gear are listed as essential medicines (obligation to fulfil).[63]

87. In the context of education, States have the core obligation to ensure the satisfaction of, at a minimum, "the most basic forms of education".[64] Also, States are to avoid measures that hinder or prevent the enjoyment of the right to education (obligation to respect) and take measures that prevent third parties from interfering with such enjoyment, such as discrimination and stigma on the part of community or family members, teachers and perpetrators of attacks against children with albinism (obligation to protect). States must take positive measures that enable and assist persons to enjoy the right to education, in particular through measures implementing reasonable accommodation (obligation to fulfil).

88. Regarding the right to work, States have the core obligation to ensure non-discrimination and equal protection of employment, especially for disadvantaged and marginalized individuals and groups, permitting them to live a life of dignity.[65] Furthermore, States must refrain from denying or limiting equal access to decent work for all persons, especially historically and currently disadvantaged and marginalized individuals and groups (obligation to respect); States are to adopt legislation or other measures ensuring that persons with albinism have equal access to work and adequate vocational training in safe and healthy working conditions[66]

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[60] Human Rights Committee, general comment No. 31 (2004) on the nature of the general legal obligation imposed on States parties to the Covenant.

[61] Ibid., para. 19.

[62] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) on the right to the highest attainable standard of health.

[63] Ibid.

[64] Committee on Economic, Social and Cultural Rights, general comment No. 3. (1990) on the nature of States parties' obligations.

[65] Committee on Economic, Social and Cultural Rights, general comment No. 18. (2005) on the right to work, para. 31.

[66] Convention on the Rights of Persons with Disabilities, art. 27.

(obligation to protect). States are obliged to provide for the right to work when individuals or groups are unable, for reasons beyond their control, to realize that right themselves using the means at their disposal (obligation to fulfil).

89. With regard to the right of persons with albinism to housing, States are to refrain from discriminatory action regarding access to housing or forced relocations (obligation to respect), while ensuring protection from any third parties or private entities interfering with access to housing (obligation to protect). Ultimately, States are to facilitate access to adequate housing and provide the same whenever persons with albinism are unable to gain access to adequate housing through their own efforts (obligation to fulfil).

90. Lastly, the right to participation and consultation with persons and groups on matters concerning them is widely recognized in international human rights law. For example, in the context of the Convention on the Rights of Persons with Disabilities, States have the duty to consult and involve persons with disabilities, including persons with albinism, regarding all policies, measures and laws concerning them.[67]

E. Action plans

91. States have clear obligations under international law to address human rights violations against persons with albinism. To ensure an efficient and effective approach, however, an immediate, coordinated and sustained approach is necessary, given the seriousness of the attacks that they face. Such an approach often takes the form of an action plan, centred on a human rights-based approach.

92. To meet both immediate and long-term goals, a dual or twin-track approach is necessary. On the one hand, in the immediate term, the human rights violations stemming from attacks and the provision of protection and support to victims must be addressed. On the other hand, effective but sophisticated strategies for the immediate-to-long term are needed to address the underlying causes of the attacks, including myths and witchcraft practices, and to mainstream the issue through a multisectoral approach consisting of the coordinated involvement of all relevant government sectors, including, but not limited to, sectors dealing with disability, health, education, social welfare and justice.

93. A multisectoral approach is necessary to expedite the integration of the diversity of issues into existing government sectors while harnessing the varied expertise of stakeholders in the development of specific programmes aimed at persons with albinism. However, action plans on albinism can be fully efficient and developed only with the meaningful participation of persons with albinism. Such participation is central not only to the elaboration of the plan, but also to its implementation and the monitoring of activities.

National action plans on albinism

94. Malawi and Mozambique, two countries that have been particularly affected by attacks against persons with albinism, adopted national action plans to address such attacks in 2015.

95. The plans include a range of measures, including education and public awareness programmes; the strengthening of community police structures; an increase in adequate police forces in the districts most affected by attacks; research to understand the root causes of attacks and trafficking in body parts with a view to

[67] Ibid., art. 4 (3).

supporting evidence-based policymaking; preventive measures and rapid prosecution of attacks; protection and social assistance for persons with albinism; psychosocial support for victims; and the review, amendment and enactment of legislation, where necessary, to ensure the protection of persons with albinism, in particular by addressing trafficking in body parts and improving proportionate sentencing through revised sentence guidelines.[68]

Regional action plan

96. In addition to the national plans of action, there is a regional approach to the attacks on and cross-border trafficking in body parts of persons with albinism. A regional action plan on albinism in Africa, to address attacks and related violations against persons with albinism in sub-Saharan Africa, covering the period 2017-2021, was recently endorsed by the African Commission on Human and Peoples' Rights in its resolution 373 (LX) 2017. Through this resolution, the Commission urged States parties to take all measures necessary to adopt and implement the regional action plan and to, inter alia, ensure protection for persons with albinism and their families.

97. The regional action plan[69] was developed between January 2016 and April 2017 by the Independent Expert and more than 200 stakeholders from the region representing organizations of persons with albinism, civil society, Governments, national human rights institutions, regional and international governmental organizations and the academic sector. Four formal consultative events were convened, including a forum in Dar es Salaam, United Republic of Tanzania, a high-level meeting in Pretoria, a consultative working group meeting in Nairobi and a panel discussion during the sixtieth session of the African Commission on Human and Peoples' Rights.

98. The regional action plan consists of recommendations made by United Nations and African Union human rights bodies and mechanisms, that have been distilled into, on the one hand, specific emergency measures in immediate response to attacks, while, on the other, triggering long-term initiatives to address the underlying causes of attacks. The measures are divided into four clusters: prevention (including public education campaigns, data collection, research on the root causes); protection (law enforcement, legislative framework, health-care workers, social welfare, monitoring and reporting of cases); accountability (combating impunity, victim support, reintegration of the displaced); and equality and non-discrimination (focal point on albinism, reasonable accommodation, access to health care, intersectionality).

99. The measures can also be implemented by integrating them into several existing, broader national frameworks, including action plans on human rights, policies on the rights of persons with disabilities and frameworks to combat racial discrimination, on access to health, on the rights of women and children and on access to justice services and victim support services. It is important to ensure, however, that the measures integrated in broader frameworks explicitly address the specificities of the challenges faced by persons with albinism. It is very important that the issue does not become "lost" among others, as the ignorance of the specificities of the rights and needs of persons with albinism has permitted the development of myths that in turn have contributed to the attacks. Indeed, the 2030 Agenda for Sustainable Development alludes to beginning all efforts with those who have been left furthest behind.

[68] See A/HRC/34/59.

[69] Full text available from www.ohchr.org/EN/Issues/Albinism/Pages/AlbinismInAfrica.aspx.

V. Conclusions and recommendations

100. **The protection and promotion of all human rights of persons with albinism are deeply rooted in international human rights law in the form of core treaties that give rise to State obligations to respect, protect and fulfil all human rights, as well as positive duties to facilitate the enjoyment of these rights. These roots are further reinforced by interpretative jurisprudence and continuous guidance issued by international human rights bodies, notably by treaty bodies and regional mechanisms as they continue to address and advocate the enjoyment of human rights by persons with albinism.**

101. **What remains is an immediate and long-term need to close the implementation gap that subsists and through which egregious human rights violations against persons with albinism have sprouted and thrive, including acts committed against their rights to life and security of person and the failure to provide adequate health care in the face of correlating high fatalities. It is the intent of the Independent Expert, having carried out this exercise of presenting the legal standards applicable to persons with albinism, to spend the coming years working with States and other partners on the implementation of the regional plan in context of the global vision designed at the outset of her mandate. All action in this regard will be carried out with a human rights approach and in cognizance of the intersecting character of applicable rights and the correlating need to induct multisectoral stakeholders in the process to guarantee both broad issue integration and specific programming to bring the furthest behind into the fold.**

102. **Accordingly, and to facilitate a partnership for the implementation of action plans and recommendations made by treaty bodies, the Independent Expert recommends that Governments:**

(a) **Adopt and implement the regional action plan as endorsed by the African Commission on Human and Peoples' Rights to ensure the effective protection and promotion of the rights of persons with albinism and members of their families;**

(b) **Address as a priority the impunity that prevails with regard to the issue, including through amendments to their legal frameworks, prompt and thorough investigations, prosecution and sentencing;**

(c) **Adopt a regional approach against impunity, taking into account the trans-border nature of elements of attacks against persons with albinism;**

(d) **Ensure reasonable accommodation measures and the full enjoyment by persons with albinism of their rights to the highest standards of physical and mental health, education, adequate housing and decent work;**

(e) **Combat the stigmatization of and discrimination against persons with albinism through a wide range of methods, including the promotion of positive information and role models and continued awareness-raising campaigns;**

(f) **Ensure the full and meaningful participation of persons with albinism in the elaboration and implementation of all measures concerning them, in particular national plans and legislation.**

103. **The Independent Expert recommends that civil society and national human rights institutions:**

(a) Continue monitoring the implementation of the rights of persons with albinism and report regularly to international mechanisms such as treaty bodies or the Universal Periodic Review;

(b) Take an active role in the implementation and promotion of action plans on the rights of persons with albinism and the inclusion of relevant action in existing programmes and strategies.

104. **The Independent Expert recommends that the international community:**

(a) Continue to address and to prioritize questions relating to the implementation of the human rights of persons with albinism, in particular given the seriousness of the violations;

(b) Examine and clarify the international legal standards applicable to trafficking in body parts;

(c) Ensure that, in particular in regions affected by attacks, action for the enjoyment of the rights of persons with albinism in incorporated into existing projects and programmes and that specific programmes are designed and given priority.